

## **BRAIN INJURY COMMITTEE **DRAFT** MINUTES**

**December 3, 2018 – 2:00 PM**

**Smyrna State Service Center, Smyrna, DE**

### **QUORUM PRESENT: 16**

**PRESENT:** Sharon **Lyons**, BIAD, Co-Chair; Andrew **Buridan**, Brain Injury Advocate/Support Group; Susan **Campbell**, Social Services Senior Administrator (DHSS/DMS); Tammy **Clifton**, DOL/ DVR, Senior Counselor (for Andrea Guest, Director); Susan **Cowdery**, LTSS Medical Director, BCBS, Highmark Health Options; George **DelFarno**, Survivor and Director, Post-Acute Medical Center (Dover); Kristin **Harvey**, DDC (obo Steve Yeatman); Karen **McGloughlin**, Director of Women's Health (for Dr. Karyl Rattay, Director); Dorothy **Prior**, Psychologist (obo Marie Nonnemacher); Dr. Ron **Sarg**, DCVA/MOAA; DLP; Jamila **Waigwa**, DHSS/DSAAPD; and Dee **Rivard**, SCPD (obo John McNeal).

**ABSENT:** Christine **Applegate**, Bayhealth Neurosurgery; Sybil **Baker**, GACEC (obo Wendy Strauss); Thomas **Cairo**, Bayhealth Neurosurgery; Debbie **Dunlap**, Parent of a survivor/Advocate; Brian **Eng**, Esquire, Community Legal Aid Society, Inc., Disabilities Law Program (obo Laura Waterland); Katie **Freeman**, DSCYF, DPBHS, Psychologist (for Robert Dunleavy LCSW); Francis **Haggerty**, Director Polytrauma & TBI Program, VAMC; **Michelle Hood**, St. Francis LIFE; Mary **Iampietro**, A. I. DuPont Children's Hospital; Dr. Charles **Jin**, (DSAMH); (obo Elizabeth Romero, Director); Dale **Matusevich**, DOE, ECE, Education Associate, Transition Services (for Mary Ann Mieczkowski); John **McNeal**, Survivor/SCPD Director; Ann **Phillips**, Chair, Parent of a survivor; Nancy **Ranalli**, Easterseals, Director of Community Outreach; Megan **Witman**, Post-Acute Medical Center.

**GUESTS** (Not able to vote or count toward quorum)

**IN-PERSON** – N/A

**TELECONFERENCE PARTICIPANTS:** Linda **Brittingham**, Christiana Care Health System (CCHS);

### **CALL TO ORDER**

Sharon Lyons called the meeting to order at 2:12 p.m.

### **ADDITIONS/DELETIONS TO THE AGENDA**

Sharon inquired if there were any additions or deletions for the agenda.

- Hearing none she proceeded to approval of past minutes.

### **APPROVAL OF PREVIOUS MEETING'S MINUTES**

Sharon inquired if everyone had sufficient time to review the minutes of our last meeting from November 5.

- Kristin Harvey made a motion to accept the 11/05 minutes as prepared that was seconded by Karen McGloughlin with voting members in attendance unanimously approving the motion.

## **OLD BUSINESS**

- Sharon inquired if anyone had old business to discuss.
  - Col. Ron Sarg stated that there is no TBI Registry Program in Delaware. He appreciated the information that Karen McGloughlin previously provided. He would like to see Brain injury information broken down by patient age and the number of cases. He added that in effect we could take the information from the numbers that Karen provided and extrapolate to get the number of TBIs that occurred this year. He advised that the report members received shows the rate.
  - In-person attendance is required by Delaware's FOIA law found under Title 29, Chapter 100, §10004 in order to remain a voting member.
- **Data Development Subcommittee Update**
  - **BIC\_DDS Members**
    - BIC\_DDS subcommittee members are Karen McGloughlin, Tom Cairo, Susan Cowdery, Ann Phillips, Andrew Burdan and Katie Freeman.
    - Karen McGloughlin advised that the DDSC members have not met since November 5. They are trying to set a meeting schedule.
    - Karen received original data from the Injury Coalition Prevention Committee.
    - She inquired about seeing their raw data and inquired about the kinds of other information that BIC's DDSC may be able to obtain; but, has not received a response.
    - This next meeting will take place on the morning of December 10.
    - Karen advised that this subcommittee is still in its beginning stages and that they plan to move forward consistently and methodically.
    - Karen advocated again to have a member of the Injury and Prevention Coalition (IPC) group as a member of the BIC.
    - This subcommittee plans to contact victims' compensation and acute care hospital discharge planners to try and obtain an agreement to share information with the BIC.
- **Traumatic Brain Injury Fund Application Review Subcommittee Update**
  - We are still in the process of trying to increase awareness of the TBI Fund availability for Delawareans with traumatic brain injuries.
  - SCPD members commented that the TBI Fund Policy was too lengthy at the November 19 SCPD meeting and sent it back to the TBI Fund subcommittee for revisions. Other comments are being sent to Dee.
  - Dee advised that she posted information about the TBI Fund availability on the State Council for Persons with Disabilities Facebook page at <https://www.facebook.com/statecouncilforpersonswithdisabilities/> and emphasized that recipients must be a Delaware resident with a traumatic brain injury as opposed to an acquired or anoxic brain injury. The maximum funding available per person per year is limited to \$7,500 with exceptions for home modifications.

- Col. Ron Sarg shared that 40% of combat casualties have dental injuries. However, the TBI Fund only covers services directly related to traumatic brain injuries.
- Members inquired if we have a brain injury declaration date through Legislative Hall and recommend this as a priority for this legislative session to increase awareness of brain injuries.
- Committee members requested that SCPD request legislation designating a day or week as Brain Injury Awareness Day/Week in Delaware.
- Members also advised Dee to search for a National Brain Injury Awareness Week so the committee could also capitalize on that for awareness.
- Committee members suggested sharing public service announcements with local television shows. A question arose; however, about who would be available to speak on behalf of the Brain Injury Committee during the interview. Committee members suggested WBOC DelMarVA Life and TV Channel 20 available at <http://www.DETVch.com>, who shares community and positive news from Delaware's three counties. They are also on Facebook at "@DeTv302".
- **Prevention and Outreach Subcommittee Structure Development Planning**
  - BIC committee members discussed planning for this new subcommittee by first sharing that BIC needs more members who are brain injury survivors involved.
  - Committee members recommended this subcommittee should focus on:
    - coordination of transportation, and
    - cross promoting the TBI Fund,
  - Committee members discuss outreach groups and organizations for the subcommittee:
    - Hospitals
    - School administrators
    - Injury Prevention Council
    - Department of Education
    - DSAAPD
    - DSAMH
    - City of Wilmington
    - Parks and Recreation
    - Boys and Girls Club; and
    - Private sports fields (However, members were informed that the Youth Concussion Act does not apply to the owners, it would apply to the sponsoring sports authority.) Additionally members inquired as to how they would even know where all of the private parks and places are that permit sports groups to play on their fields.
    - New Castle, Kent and Sussex Counties all list parks run under their authority on their websites as does the State of Delaware, Division of Parks and Recreation under DNREC.
  - Committee members agreed that we need PSAs.
  - We need to design a flyer to place information signs at local parks similar to DelDOT's portable signs for the highways.

- This subcommittee should take data from the Data Development to share. Subcommittee in order to develop information sharing, flyers, brochures, and increase brain injury outreach.
- Committee members suggested reaching out to the State Insurance Commissioner to see if there is a way to mandate the sharing of TBI data with the State of Delaware.
- Sharon Lyons is doing outreach on her own relating to concussions and brain injuries. Sharon asked if any members are willing to assist her or extend this outreach to lower Delaware.
- Committee members suggested that the **Prevention and Outreach Subcommittee** reach out to NovaCare Corporate Sponsors, Wilmington BlueRocks and providers who work with brain injury patients to share information on concussions, brain injuries and the Traumatic Brain Injury Fund once they are formally established.

## NEW BUSINESS

- Sharon continued her outreach to the following:
  - Jeffrey Ferrante about the possibility of his becoming a member of the BIC and the Brain Injury Association of Delaware (BIA of DE) Board of Directors.
  - Sharon recently exhibited at the Epilepsy Conference and mentioned that she has not seen A. I. DuPont Nemours Children's' Hospital exhibiting at any of the conferences or events in quite a while, including school resource fairs. Sharon spoke with Steve Falchek to see if he could possibly find someone who is willing to regularly attend BIC meetings in-person. Sharon also plans to reach out to Ann Wright to obtain a point of contact.
  - Sharon informed committee members that she received an email from someone who is working on his advanced degree in college that is offering to translate written documents into Spanish for the BIA of DE. However, they would still need a way to communicate with Spanish speaking clients who call into the office. Committee members advised that they typically connect to an interpreter through the language line.
- Committee members inquired about BIC membership from hospitals in southern Delaware since we do not have representation from that area. BIC members recommended to reach out to contacts from hospitals in lower Delaware.
- Committee members felt that it is important to have the biggest stakeholders in Delaware as a part of the BIC.
- Michelle Hood is no longer with Saint Francis Life.

## ANNOUNCEMENTS

- Andrew Burdan shared a story about someone he met recently who works at the County Bank in Sussex who advised that they have several customers with brain injuries. One particular customer lives in Milton and these customers really need support when dealing with their activities of daily living including handling finances.

- Andrew suggested that BIC members involve rehab specialists in the area.
- Sharon recommends everyone she speaks with who has a brain injury to Dr. Anne Mack at Christiana Care who specializes in brain injuries.
- Committee members discussed the use of a Lost and Found Guide of what every brain injury survivor wants you to know and the use of the Mayo Portland Adaptability Index Score to help to determine whether or not people fit the criteria. Some people with brain injuries are not approved for Long Term Medicaid. This new assessment tool screens those with brain injuries who otherwise would have been denied. Lisa Zimmerman could follow up to ensure that this assessment is still being utilized.
- Sharon Lyons requested members to send private entity names to her for her to share information with.
- Members asked what is the BIC doing for people who are homeless and who may have a brain injury?
  - Dover InterFaith Group works tirelessly and has a major impact on the homeless issue in Kent County.
  - Executive function is usually hit pretty hard for survivors of brain injuries. A suggestion was made to contact the New Sun Behavioral Health n Georgetown?
  - The core competencies that are needed by individuals with brain injuries need to be shared among the different groups. Can resources for that specific population can it be morphed to work with other populations?
  - There has to be a campaign that asks the right questions. E.g. Have you suffered a brain injury? This would allow the BIC DDSC to break down demographics prior to beginning to work with the acute-care hospitals.
  - Need to ensure follow-up after acute care discharge for individuals with a brain injury from hospitals and rehabilitation centers. Committee members agreed that something or someone should follow-up in 30 to 60 days following a patient's discharge from a hospital to ensure that they are receiving the services that they need. Most patients with brain injuries, their families and personal caregivers don't know yet what they need and time is of the essence for recovery.
  - Committee members suggested marketing and outreach to families and professionals specifically related to individuals with brain injuries.
- The Data Development Subcommittee plans to review how other states set-up and run their brain injury registries.
- Committee members felt that getting testimony from survivors is extremely valuable. These individuals really need assistance and don't know what to ask for. Committee members felt that this is a good project for the **Prevention and Outreach Subcommittee**.
- Sharon advised that she receives calls from Bryan-Mawr, Einstein Hospital, Moss and Megee Rehabs looking for resources for their Delaware patients.
- Post-Acute Medical Center is in the process of looking for a Neuropsychologist. They will accept patients with brain injuries who also have mental health issues. They recognize that combative issues are huge.

- Committee members inquired if Sharon keeps a list of the types of services that the hospitals and rehabilitation centers are requesting? Sharon advised that most of the requests are for PT/OT/SLP, Cognitive Assessments and continuity of care. Brain injury patients are losing valuable time when these needs are not quickly addressed. Not having a Neuropsychologist in Delaware is a huge issue.
- Committee members discussed a mom with a TBI of her own who needed a break as a mom from raising her children who have special needs. Committee members suggested Easterseals Respite Care.
- Sharon shared information about the 2019 Brain Injury Conference - Joining Forces Sharing Voices: A Discussion of Challenges, Education, Supports, and Diversity with Survivors, Caregivers, and Professionals. Sharon will share a "Save the Date" with Dee for distribution to BIC members. The conference is scheduled for Friday, March 8 at Dover Downs Hotel & Conference Center.
  - Committee members suggested a Domestic Violence speaker that can tell about the consequences of domestic abuse for a break out session.
  - The new medical director for Post-Acute Medical is their keynote speaker. Sharon is sending him a speaker package this week.
  - Felicia Conners is speaking on diversity.
  - Twara Good is also excellent and she works at Rusk.
  - Dr. Mills is speaking as part of the pediatric concussion panel and BIA of DE also plans to have an adult concussion panel.
  - Katie Freeman is going to speak at the conference.
  - Sharon would like to have a nurses panel.
- Kristin Harvey shared information about the 2019 LIFE Conference DE that is scheduled on January 31. This is Delaware's premiere Disabilities Conference.
  - The Developmental Disabilities Council (DDC) reallocated funds from their federal grant for scholarships for Delaware adults with disabilities to be able to attend the 2019 LIFE Conference that will also assist with transportation, interpreters, and Braille print. This scholarship is only for adults with disabilities who reside in Delaware.
  - Kristin cannot send out information on the scholarship via email because people misunderstand the poster. She requested that members have interested people contact their office or email [info@lifeconferencede.org](mailto:info@lifeconferencede.org) or call Lorraine at 508-539-3530.
  - Kristin shared that DDC has always give out scholarships for people who requested them. This is the first year that they are actively promoting scholarships for adults with disabilities.
- Caregiver relief in Delaware is typically geared toward seniors; however, Birth to 3 and Child Development Watch has a panel to determine if they can move funds over to help fund attendance to the LIFE Conference for families.
- Sharon advised that the Brain Injury Conference sponsors brain injury survivor's attendance to the Brain Injury Conference.
- Sharon shared that the Concussion Conference with the NFL is scheduled for April 6 at the Duncan Center in Dover and that they invited her to speak.

- This conference presentation will have a dual sided perspective with NFL players who have sustained concussions along with the providers who treat them.
- Sharon provides outreach on concussions. Bayhealth asked her to speak to Bayada Nurses about concussions.
- BIAD is hosting The Family Shade breakfast at the BIA of DE Office in Dover. 8:30 - 12:00 followed by their meeting.
- Sharon is looking into contacting a man with a DAI in PA who facilitates -- "Restart Your Life, Renew Your Mind", monthly events for people with brain injuries.
- Sharon advised that BIA of DE is searching for a new executive director sharing that they received some pretty amazing resumes. The Board of Director's is hoping to fill this position ASAP.

#### **ADJOURNMENT**

- Karen McGloughlin made a motion to adjourn that Kristin Harvey seconded. Sharon called for discussion and hearing none, she called for a vote by committee members present who unanimously approved the motion to adjourn.
- With no further business to discuss the meeting adjourned at 3:06 p.m.

#### **NEXT MEETING**

The next Brain Injury Committee meeting is scheduled for  
**Monday, January 7 at 2:00 p.m.**, in the  
Smyrna Rest Area Conference Room